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ABSTRACT

Aging individuals are most often cared for by a spouse or middle-aged child, usually a daughter. As the aging population increases, as longevity increases along with the likelihood of chronic and disabling conditions, women will be facing many special problems related to their role as caregiver. Many women who are serving as caregivers to their ailing husbands or other family members are also suffering from a chronic disease or disability themselves. These women are the "unidentified patients" in home health care, caregivers who have chronic conditions themselves and are patients in their own right, though functioning at a higher level of autonomy and independence than the identified patient. How caregivers feel about the caregiver role often depends upon the way in which the caregiving responsibility has been assigned to them, their expectations regarding the responsibility, and expectations of others regarding the role. Quite often there is a crisis in which the role is assumed quickly without the luxury of time to review the role. Families are often unprepared for the 24-hour responsibility and restrictions of caregiving. Continuous or nighttime supervision is perceived as one of the most difficult services for families to provide. Caregivers have a threshold beyond which it is difficult for them to increase their supportive services. There is a need for a mechanism to raise the status of caregiving while at the same time focusing some care, attention, and concern to the caregiver as well as to the patient. (NB)

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# THE "UNIDENTIFIED PATIENT" IN HOME HEALTH CARE

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THE "UNIDENTIFIED PATIENT" IN HOME HEALTH CARE

It is no longer news that the aging population is on the increase in this country. It is estimated that by the year 2000 the elderly will number 35 million representing 13.8 percent of the total population or every eighth American. (LOWY, 1979:23) With the increase in the aging population comes an increase in mental and physical problems. A 1979 national survey reported that nearly 80 percent of the elderly population have at least one chronic condition (ATLANTA REGIONAL COMMISSION, 1984) It is estimated that 10.7 million people over age 65 (approximately 46%) have some limitation of activity due to chronic conditions. (BRODY, 1985:21) The most common chronic conditions that affect older people at a much higher rate than younger people are arthritis, hypertension, visual impairment and diabetes. Studies show 10.3 million people suffer from arthritis. (BRODY, 1985:24) Paired with chronic illness are physical limitations and impairments which often in time develop into a disability. Very few people reach advanced old age without the need for some assistance due to physical or mental disability. The number of older individuals living in the community and in immediate need of home care services has been estimated at 14 to 18 percent of the population or 3.2 to 3.9 million persons. (KAYE, 1985:409)

As we look at the aging population based on the 1980 Census Bureau Data we see 26.8 million Americans who are 65 or older. There were 16.0 million women and 10.8 million men. (LOWY, 1979:24) Most older men were married (78%) and most older women were widows (51%). There were

five times as many widows as widowers. (LOWY, 1979:32) Minkler and Stone report three out of every five women age 65 and over (or about 63%) are without a spouse, whereas in contrast three out of every four men in this age category are married and living with their wives. (MINKLER AND STONE, 1985)

The 1982 Long Term Care Survey indicates that 1.1 million people received paid home-health care during 1982 served by 5000 agencies. (LIU, MANTON & LIU, 1985) In its annual report for 1985, the Visiting Nurse Association, only one of several home health agencies in Atlanta, reported 5,482 admissions and 49,028 visits for the year. It is estimated that by 1988 total revenue for home health care products and services will reach $12.2. billion. (HOSPITALS, 1984)

Only 5% of community-residing adults aged 65 - 74 need the help of another person in one or more of seven basic activities of daily living. These percentages double for those age 75 - 84. It is estimated that one-third of the population over 85 need assistance. (ORY, 1985:14) These figures are very significant when we realize that the four generation family is becoming increasingly common with a generation of frail elderly in their 80's depending on their children of 60.

Aging individuals are most often cared for by a spouse or middle aged offspring, usually a daughter. Women find themselves in the caregiving role because they generally marry men older than themselves and also live longer (7.8 years longer than men). (MINKLER & STONE, 1985) As the aging population continues to increase, as longevity increases along with the likelihood of chronic and disabling

conditions, women in our society will be facing many special problems. It is probable that at some point in their lives they will become the caregiver for a sick and ailing relative or spouse - a job for which they have received no training and very little support. Golodetz describes the role of caregiving:

> "She is not trained for her job a priori. She may have little choice about doing the job. She belongs to no union or guild, works no fixed maximum of hours. She lacks formal compensation, job advancement and even the possibility of being fired. She has no job mobility. In her work situation she bears a heavy emotional load, but has no colleagues or supervisor or education to help her handle this. Her own life and its needs compete constantly with her work requirements. She may be limited in her performance by her own ailments." (GOLODITZ, EVANS, HEINRITZ & GILISON, 1969)

When the older person is widowed the women in the next generation become the principal caregivers. Elaine Brody refers to these women as "women in the middle." (BRODY, 1981) They are also commonly referred to as "the sandwiched generation."

This paper will examine the special needs and problems of the "unidentified patient" in home health care. These are the women who are serving as caregivers to their ailing husbands or other family members who are suffering from a chronic disease or disability and who warrant the label, "unidentified patient," as many of them have chronic conditions themselves and are patients in their own right, though functioning at a higher level of autonomy and independence than the identified patient. Gengler and Goodrich refer to these women as "the hidden patients" stating that the "spouse is often as needy as the patient." (FENGLER & GOODRICH, 1979)

The following questions will be addressed:

1. Claiming the sick role - its implication for patient and caregiver.
2. The type of maintenance functions women are providing for impaired family members - what special skills and talents are required?
3. Restrictions in providing care - sense of burden and how it is experienced.
4. Rewards and gratifications in the role of caregiver.
5. Need for more supportive services to be utilized in future planning.

It is also pertinent to ask - who will be there to care for the caregiver when it is her turn to "become the patient"?

Anthropologists tell us that certain things happen when a person "claims the sick role." The patient has two principal rights: exemption from normal social role responsibilities and care until recovery. There is no expectation that by an act of decision or will the person will "pull himself together" without help. The patient is not held responsible for his condition. (FOSTER & ANDERSON, 1978:154) Sociologist Talcott Parsons has developed a sick role model in which he describes illness as "a form of deviant behavior that provides a socially sanctioned and institutionalized way to withdraw from the demands and stresses of everyday life." The behavior of an ill person is often marked by passivity, submission and dependency. (PARSONS, 1951:285)

It is also not unusual that the role of healer or shaman is involuntary - something that is forced on a reluctant individual by the spirits who confer to them the powers the curer will use. One could make the analagy that often caregivers like shamans are thrust

into unfamiliar and unwanted roles out of necessity. Because the implied expectation of society is that when one person claims the sick role, a complementary person must claim the caregiver role.

Parsons further discusses the attitudes that medical caregivers assume when providing care. The term "affective neutrality" refers to the physician as applied scientist being expected to treat a problem in objective, scientifically, justifiable terms. (PARSONS, 1951:435) When we look at the role of caregiver, we see anything but "affective neutrality." What we see upon close observation is instead "subjective activism," a strongly disposed temperament exhibiting vigorous action and involvement toward a desired end.

Frankfather describes sixteen categories of activities most commonly associated with the role of caregiver. Those activities most frequently provided include: preparing meals, light housecleaning, administering or supervising medication and assisting or supervising grooming and personal hygiene. We also know that for meals to be prepared, food must be purchased and for medications to be administered, they must first be obtained. Continuous or nighttime supervision is perceived as one of the most difficult services for families to provide. (FRANKFATHER, SMITH, CARO, 1981:32)

We know of our observations of individuals in many settings that our feelings about the jobs we perform and the roles we assume often have to do with several factors:

1. The way in which the responsibility is assigned to us,
2. Our expectations regarding the responsibility (discrepancies in role requirements and our actual capabilities), and
3. Expectations of others in our environment regarding the role.

These factors become important in trying to measure or assess the feelings of burden associated with the role of caregiver. Caregivers are often thrust into their role when a complementary family member "claims the sick role." Quite often there is a crisis in which the role is assumed quickly without the luxury of time to "review the job description or update one's qualifications." One woman described her situation to me:

> "My husband had a stroke one afternoon and we took him to the hospital. When he came home, he was paralized and couldn't talk. All of the therapy helped some; he can talk now even though his speech is slurred and he can feed himself. We were going to tour Canada that summer, but I sold our camper. I've been taking care of him ever since."

Often, individuals adjust better to situations or events that are perceived as "expected" in which one has time to cognitively plan for various alternatives. Unexpected or unplanned events are seen as more stressful.

Sometimes families have "good intentions" but are unprepared for the twenty-four hour responsibility and restrictions of caregiving. As time wears on they become more and more angry about this heavy responsibility and guilty about expressing the anger. This may be related to the long-term nature of the problem. Contrast a family's attitude with an acute illness as compared with a long-term chronic debilitating condition. When a time limited crisis occurs (for example, a person with lung cancer who has four months to live), it is often perceived as a dramatic challenge to the family and the community. Family members mobilize; community help is evident; there is a galvinizing sense of the dramatic and the heroic in the

challenge of coping with a crisis with a time limit. There are gifts of food, flowers, relatives from distant places often travel to "see my brother for the last time." Because it is time limited, it is frequently perceived as less of a burden by family than an ongoing long-term responsibility that is seen "without end." Fengler notes that a long illness produces a significantly greater effect on the family than an acute illness. (FENGLER & GOODRICH, 1979)

Poulshock and Deimling state that the concept of burden is synonymous with the effects of caregiving. Their study examines burden as a mediating force between the elder's impairments and the impact that caregiving has on the lives of caregivers and their families. (POULSHOCK & DEIMLING, 1984) Varying responses may be received by a caregiver from his family or environment ranging from warm thanks to anger. Whether expressed actively or passively, the concept of hostile dependency is nothing new to social workers and is often the result of being enmeshed with a dependent person. Dependency introduces a high potential for conflict.

Sometimes the feedback from significant others in the environment, though meant in a positive way, may be framed negatively. People often remark, "It must be awful being tied down all the time," or "You couldn't pay me to do what you're doing," or "You need more rest." These may be interpreted by the caregiver as negative and discouraging.

> "My daughter tells me I ought to get up early every morning and take a walk, but she doesn't know what it's like to have to get up three and four times every night. I'm tired every morning."

In my visits I usually take some time at the end of a visit to comment on the positive aspects of care that I observe. Almost

invariably a caregiver seems surprised, often apologetic about some aspect of care with which they are not comfortable and sometimes self-deprecating. "I know it could be done better, I just do the best I can." Their ears seem to long for the appreciation and affirmation of a job well done.

The family as a whole often has difficulty in assuming the caregiving role because of many factors:

1. The geographic dispersion of families today in America means that aging parents are often separated by many miles from children or other family who would previously have provided support.

2. The increase of women in the workforce means that family members often have other responsibilities to manage which leave them unavailable for the 24-hour responsibility of caregiving.

3. There are often long-standing intergenerational conflicts or strained relationships within families which become more severe with the advent of chronic illness.

4. Unresolved sibling rivalry and conflicts about what type of plans should be implemented or what kind of service is needed.

5. The financial difficulties brought about by restricted income, disability, large medical bills and inaccessibility to preferred shopping.

When caregivers were asked by Marcus and Jaeger for an assessment of caregiving, four themes emerged as an answer to the probe "what makes a day easy/difficult?".

1. The routine - easy when relief from it.

2. Isolation and being tied to the house - difficult to tolerate.

3. Visitors ease the burden.

4. Patients mental and physical state - "its easier when he's himself." (MARCUS & JAEGER, 1984)

Why are families motivated to accept the role of caregiver? Often out of a feeling of affection for the handicapped individual. Positive previous experience and the promise of family assistance are motivating factors. Some families describe it as coming from a feeling of "personal integrity" and commitment to the relationship, "a purpose for living.

> "I sit here and I remember all the good times we had together. I know, if it was me lying there, he'd do the same for me."

Others feel a sense of duty, indebtedness, of obligation. There is also a feeling of embarrassment or shame about "putting my husband in a nursing home." Even in families where there has been anger and strained feelings, these are sometimes diminished when one party assumes the dependent role. One daughter stated:

> "He always seemed so strong, always in charge. When I see him sitting there so helpless, all I want to do is help."

I have also observed that caregivers have a threshold beyond which it is difficult for them to increase their supportive services. One woman (Mrs. Smith) took care of her husband quite well for seven years, but when her husband's appetite decreased and he no longer enjoyed her cooking coupled with more disruptive behavior at night-time, she felt she could no longer "take it anymore." Sometimes caregivers wish to disclaim or relinquish their role but are unsure about how to do this. After all, they are "expected to do it." One of the signs is expression of a series of complaints about their own health. After one visit Mrs. Anderson followed me to my car stating:

> "I don't know how much longer I can go on this way. My blood pressure goes up anddown. I get so dizzy sometimes I have to lie down. I went to the doctor and he said I'm almost as sick as he is; he told me I need to be off my feet."

The underlying message is a plea for her own dependency needs to be met.

"Old people turn first to their families for help, then to neighbors, and finally to the bureaucratic replacements for families, social workers, ministers, community agencies." (SHANAS, 1979) When asked where they prefer to be in case of illness or disability, the individual response is almost always "at home." At home there is more attentiveness to individual needs, routines, whims. Even performing daily rituals show a tolerance for ideosyncratic preferences. One wife reports:

> "He wakes up every morning at 6:30 and he won't do anything till he's had a cup of coffee. I always open the blinds so he can look out at the birds. We wait for the mail to come at 10:00, and I always read it to him."

Flexibility and tolerance seem to be two valued characteristics of family care which cannot be duplicated by institutional care. Food preparation and activities of daily living often exhibit these two features.

We are seeing an increasing need for long-term care services at a time when public resources continue to decline. Public policy increasingly expresses the expectation through such avenues as the Family Responsibility Amendment to Medicaid, that family caregivers will continue to provide care for the frail elderly in their home.

Expenditures for health care for older persons represent 33% of total health care expenditures in the U.S. today even though the elderly account for only 11% of the population. (BINSTOCK, 1984:5) It is well known that public policy and social agencies have long stressed the benefits of home health maintenance forthe disabled and impaired elderly. Yet of the ,ublic funds targeted for the elderly, 90% are channeled to institutional care which serves only 5% of the elderly population. (LOWY, 1979) Chronic illness has been described as the major health problem for the elderly yet acute care predominates with 40% of health resources for people of all ages being, consumed by hospital care. (BRODY, 1985) These disparities need to be addressed, and it is up to professionals who see the needs and who understand the delivery system to become advocates for the elderly purchasers of supportive services who lack bargaining power in the marketplace.

Some of the suggestions for assisting families in providing care for impaired members have to do with help in "accessing the system." Sometimes families flounder and resist seeking help because they do not understand how to enter the system and how to ask for help. It has been recommended that there be financial reimbursement for families who care for a chronically ill individual. Certainly a mechanism to raise the status of caregiving at the same time focusing some of our care, attention and concern to the caregiver as well as the patient is called for. We are already aware that there is a need for more availability of supportive services that are already being offered such as meals on wheels, day-care, homemaker services, and respite care. Some families feel a "night care center" or help available on

weekends or over the entire 24-hours would be of help. Nursing homes and hospitals could initiate intermittent readmission policies. Home health agencies may need to staff around the clock similar to hospital staffing patterns to address these special needs of families. Supportive networks for caregivers would provide opportunities for socialization and support. The role of caregiving is so tedious and consuming that caregivers forget to take care fo themselves. When asked about their own grooming (hair, nails) or what do you do for fun or to relax, there is often no response. We advise mothers who are caregivers to young children to "take time off," "take care of yourself," but there seems to be little focus on this philosophy in the role of the older caregiver. Marcus and Jaeger report almost 50 percent of all caregivers mentioned no activities related to "care of themselves" or their own leisure. (MARCUS & JAEGER, 1984)

As women, we know that it is likely that we will be called upon to participate in the care of an elderly relative or spouse. We are candidates for the caregiver role and as health care professionals, we have the knowledge, the skills, and the experience to bring to bear on the problems we forsee caregivers facing. There is a need to focus our creative energy on the problem at a time when we, vigorous and imbued with power, are able to exercise our influence in shaping public policy.

Elaine Brody calls for a revised contract between the family and the formal support system due to the fact that there is a larger packet of responsibility to be distributed. (BRODY, 1981)

Rosalie Kane neatly summarizes:

"Family caregivers indisputably need help with their tasks. Some need technical information, some need backup assistance, some need encouragement and social recognition. This leads to public policies on education, support groups, and ancillary services. . . Genuine assistance to caregivers may not be a cheap proposition /_but_/ family caregivers cannot be supported by cheerleading alone." (KANE, 1985)

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